

DRAFT FRAMEWORK FOR THE NATIONAL PLAN TO ADDRESS ALZHEIMER'S DISEASE

Goal 1: Prevent and Effectively Treat Alzheimer's Disease by 2025

Research continues to expand our understanding of the causes of, treatments for, and prevention of Alzheimer's disease. Basic research elucidates the molecular and cellular process underlying AD, allowing the identification of potential targets for intervention. Through the drug development process and the translation of behavioral interventions, treatments are tested in preclinical experiments for their effectiveness. Promising interventions are further refined and tested to ensure they are safe and effective for the public. While the ultimate goals are to develop effective prevention and treatment modalities by 2025, ongoing research and clinical inquiry can inform our ability to delay onset of Alzheimer's disease, minimize its symptoms, and delay its progression. Under this goal, HHS will prioritize and accelerate the pace of scientific research and ensure that as evidence-based solutions are identified they are quickly translated, put into practice, and brought to scale so that individuals with Alzheimer's disease can benefit from increases in scientific knowledge.

Strategy 1.A: Identify Research Priorities and Milestones

Research agencies undertake research planning processes on an ongoing basis, but a special effort is needed to identify the priorities and milestones to achieve Goal 1 and ensure that appropriate stakeholders are involved in the planning process. In May 2012, the National Institute on Aging (NIA) of the National Institutes of Health will convene a research summit to provide expert input into identification of research priorities, to explore public and private research collaborations, and to establish strategies and milestones for an ambitious plan to slow progression, delay onset, and prevent Alzheimer's disease. The summit will include national and international experts in Alzheimer's disease and dementia research, public and private stakeholders, and members of the Advisory Council on Alzheimer's Research, Care, and Services. Summit proceedings will be open to the public.

Strategy 1.B: Enhance Scientific Research Aimed at Preventing and Treating Alzheimer's Disease

HHS and its Federal partners will continue to aggressively conduct clinical trials on pharmacologic and non-pharmacologic ways to prevent Alzheimer's disease and manage and treat its symptoms. HHS will build on recent advances and expand research to identify molecular and cellular mechanisms and genetic research to identify risk and protective factors. To achieve this strategy, new partnerships and outreach efforts may be needed to ensure that enough people are enrolled in clinical trials to examine the effectiveness of promising interventions.

Strategy 1.C: Accelerate Efforts to Identify Early and Presymptomatic Stages of Alzheimer's Disease

Significant advances in the use of imaging and biomarkers in brain, blood, and spinal fluids have made it possible to detect the onset of Alzheimer's disease, track its progression and monitor the effects of treatment in people with the disease. Without these advances, these neurodegenerative processes could only be evaluated in non-living tissues. Accelerated research will improve and expand the application of biomarkers in research and practice. These advances have shown that the brain changes that lead to Alzheimer's disease begin up to 10 years before symptoms. Identifying imaging and other biomarkers in presymptomatic people will facilitate earlier diagnoses in clinical settings, as well as aid in the development of more efficient interventions to slow or delay progression.

Strategy 1.D: Coordinate Research with International Public and Private Entities

To facilitate communication and collaboration, build synergy, and leverage resources, it is imperative that research across nations and across funders be coordinated. All funders could benefit from a comprehensive inventory of research investments to address AD. Similarly, better international coordination may help leverage resources and expand the impact of research findings.

Strategy 1.E: Facilitate Translation of Findings into Medical Practice and Public Health Programs

Currently, promising research and interventions are published in the research literature and presented at scientific meetings. Additional steps are needed to highlight promising findings and to facilitate dissemination and implementation of effective interventions to the general public, medical practitioners, industry, and public health systems quickly and accurately. This may require new partnerships within the Federal Government and with the private sector, and outreach through new mechanisms.

Goal 2: Enhance Care Quality and Efficiency

Providing all people with Alzheimer's disease with the highest-quality care in the most efficient manner requires a multi-tiered approach. High-quality care requires an adequate supply of professionals with appropriate skills, ranging from direct-care workers to community health and social workers to primary care providers and specialists. High-quality care should be provided from the point of diagnosis through the end-of-life and in settings including people's homes, doctor's offices, hospitals, and nursing homes. Care quality should be measured accurately and coupled with quality improvement tools. Further, given the complex care needs of people with Alzheimer's disease, high-quality and efficient care is dependent on smooth transitions between care settings and coordination among health and long-term care service providers.

Strategy 2.A: Build a Workforce with the Skills to Provide High-Quality Care

The workforce that cares for people with Alzheimer's disease includes health and long-term care providers such as primary care physicians; specialists such as neurologists, geriatricians, and psychiatrists; community health workers; social workers; and direct-care workers like home health aides and certified nursing assistants, who provide care at home or in long-term care facilities. Major efforts by both VA and the Health Resources and Services Administration (HRSA), including expanded training opportunities created in the Affordable Care Act, support geriatric training for physicians, nurses, and other health workers.¹ Enhanced specialist training is also needed to prepare these practitioners for the unique challenges faced by patients with Alzheimer's disease. Work is needed to expand the capacity of the primary care community to care for patients with Alzheimer's disease and dementia-specific capabilities within the direct-care workforce need to be expanded and enhanced.

Strategy 2.B: Ensure Timely and Accurate Diagnosis

Far too many people with Alzheimer's disease are not diagnosed until their symptoms have become severe.² Timely diagnosis gives people with the condition and their families time to plan and prepare for the future, leading to more positive outcomes for both.^{3,4} For many, the inability to access health care due to a lack of insurance is a major concern. This is particularly important for individuals with younger-onset disease who may not yet be eligible for Medicare. Much of that insecurity will be alleviated as the Affordable Care Act, with its elimination of pre-existing conditions limitations, is implemented. Even with access to affordable care for individuals, the health care workforce needs tools that can help ensure timely and accurate diagnoses. Research has helped identify some assessment tools that can be used to rapidly assess patients showing signs and symptoms of Alzheimer's disease and to help health care providers make a diagnosis or refer for further evaluation.⁵

Strategy 2.C: Educate and Support Patients and Families Upon Diagnosis

Often, even though a physician has identified cognitive impairment, the patient and his or her family are not told of the diagnosis.⁶ Further, once a diagnosis is made and disclosed, as few as half of patients and families receive counseling, support, or information about next steps.⁷ This information is important, especially for early-stage patients who experience positive outcomes when physicians are involved in planning and advance care counseling.⁸

Strategy 2.D: Identify and Implement High-Quality Dementia Care Guidelines and Measures Across Care Settings

Guidelines for delivery of high-quality care and measures of quality are needed to ensure people with Alzheimer's disease receive high-quality care in the many different settings where they are treated. These guidelines should be tailored to the stages of the disease and cover the myriad care settings in which care is delivered, such as in the home, physician's office, and long-term care facility. These guidelines should also take into account how care might be modified in the context of co-occurring chronic conditions in people with Alzheimer's disease. Quality measures should be based on such guidelines and track whether recommended care is being provided.

Strategy 2.E: Ensure that People with Alzheimer's Disease Experience Safe and Effective Transitions Between Care Settings and Systems

A transition between providers and care settings is a complex time of care delivery for all patients but especially for frail elders or other individuals with Alzheimer's disease. Transitions include moves into acute care hospitals, from hospitals to post-acute settings such as skilled nursing facilities or the home, or from nursing facilities to hospitals. People with Alzheimer's disease are at high risk of adverse events due to poor communication and other care process deficiencies during their frequent transitions.⁹

Strategy 2.F: Advance Coordinated and Integrated Health and Long-Term Care Services and Supports for Individuals Living with Alzheimer's Disease

Coordinating the care received by people with Alzheimer's disease from different providers can help reduce duplication and errors and improve outcomes.¹⁰ Despite a general consensus that care coordination is important, more research is needed to determine how best to provide such care in a high-quality and cost-efficient manner. These answers will help in the implementation of care coordination models for people with Alzheimer's disease.

Strategy 2.G: Improve Care for Populations Disproportionally Affected by Alzheimer's Disease

Three groups of people are unequally burdened by Alzheimer's disease: People with younger-onset Alzheimer's disease, racial and ethnic minorities, and people with intellectual disabilities. Approximately 200,000 Americans have younger-onset Alzheimer's disease, which is characterized by symptoms prior to age 60. Because Alzheimer's disease primarily affects older adults, the younger population faces unique challenges with diagnosis, care, and stigma. Other populations disproportionately burdened by Alzheimer's disease are racial and ethnic minorities who are at greater risk for developing Alzheimer's disease and face barriers to care after onset. Finally, people with certain intellectual disabilities almost always develop Alzheimer's disease as they age.

Goal 3: Expand Patient and Family Support

People with Alzheimer's disease and their families need supports that go beyond the care provided in formal settings such as doctor's offices, hospitals, or nursing homes. Families and other informal caregivers play a central role here. Supporting people with Alzheimer's disease and their families and caregivers requires giving them the tools that they need, helping to plan for future needs, and ensuring that safety and dignity are maintained.

Strategy 3.A: Ensure Receipt of Culturally Sensitive Education, Training, and Support Materials

Caregivers report that they feel unprepared for some of the challenges of caring for a person with Alzheimer's disease--for example, caring for a loved one with sleep disturbances, behavioral changes, or in need of physical assistance can be an enormous challenge.¹¹ Giving caregivers the information and training that they need in a culturally sensitive manner helps them better prepare for these and other challenges. Examples of potential actions under this strategy include identifying the areas of training and educational needs, identifying and creating culturally-appropriate materials, distributing these materials to caregivers, and using information technology to support persons with Alzheimer's disease and their caregivers.

Strategy 3.B: Enable Family Caregivers to Continue to Provide Care While Maintaining Their Own Health and Well-Being

Even though informal caregivers usually prefer to provide care to their loved ones in their home or other community settings, eventually the round-the-clock care needs of the person with Alzheimer's disease often necessitate nursing home placement. While they are providing care, supports for families and caregivers can help lessen feelings of depression and burden and help delay nursing home placement.^{12,13,14} Examples of actions to further support informal caregivers are identifying their unmet support needs; developing, disseminating and expanding interventions; and highlighting supports during crisis situations.

Strategy 3.C: Assist Families in Planning for Future Long-Term Care Needs

The vast majority of people do not think about or plan for the long-term services and supports they will need until they experience a disability or Alzheimer's disease. Many Americans incorrectly believe that Medicare will cover most of the costs of these supportive services.^{15,16} Unfortunately, by the time care is needed, it is difficult to get coverage in the private long-term care insurance market, and options are limited.¹⁷ Educating people about their potential need for long-term services and supports and the significant advantages of planning ahead for these services encourages timely preparation. Planning ahead can help ensure that individuals with Alzheimer's disease receive care in the setting they prefer and that their dignity is maintained.

Strategy 3.D: Maintain the Dignity, Safety, and Rights of People with Alzheimer's Disease

People with Alzheimer's disease are particularly vulnerable to financial exploitation, physical or emotional abuse, and neglect both at home and in residential care facilities.¹⁸ Reports of elder abuse are handled by state Adult Protective Services, which is charged with responding to and resolving alleged abuse. State survey and certification agencies investigate abuse in licensed facilities, which may include nursing homes, assisted living facilities, and board and care homes. AoA's National Long-Term Care Ombudsmen are advocates for residents of nursing homes, board and care homes, assisted living facilities, and similar adult care facilities and can help address issues related to potential abuse or neglect.

Goal 4: Enhance Public Awareness and Engagement

Most of the public is aware of Alzheimer's disease: more than 85 percent of people surveyed can identify the disease and its symptoms. Alzheimer's disease is also one of the most-feared health conditions. Yet there are widespread and significant public misperceptions about diagnosis and treatment.¹⁹ These misperceptions lead to delayed diagnosis and to people with the disease and their caregivers feeling isolated and stigmatized. Enhancing public awareness and engagement is an important goal because it forms the basis for advancing the other goals of the National Plan. A better understanding of Alzheimer's disease will help engage stakeholders who can help address the challenges faced by people with the disease and their families. These stakeholders include a range of groups such as health care providers who care for people with Alzheimer's disease and their caregivers, employers whose employees request flexibility to care for a loved one with the disease, women's and other groups whose members are caregivers, and broader aging organizations. The strategies under this goal are designed to educate these and other groups about the disease.

Strategy 4.A: Educate the Public about Alzheimer's Disease

Greater public awareness of Alzheimer's disease can encourage families to seek assessment, reduce isolation and misunderstanding felt by caregivers, and help link people in need to accurate information, resources and services.

Strategy 4.B: Work with State and Local Governments to Improve Coordination and Identify Model Initiatives to Advance Alzheimer's Disease Awareness and Readiness Across the Government

State and local governments are working to help address challenges faced by people with Alzheimer's disease and their caregivers. Nineteen states and a handful of local entities have published plans to address Alzheimer's disease that cover many of the same issues as the National Plan.²⁰ Leveraging the available resources and programs across these levels of government will aid in the success of these efforts.

Goal 5: Improve Data To Track Progress

The Federal Government is committed to better understanding Alzheimer's disease and its impact on people with the disease, families, the health and long-term care systems, and society as a whole. HHS will make efforts to expand and enhance data infrastructure and make data easily accessible to federal agencies and other researchers. This data infrastructure will help HHS in its multi-level monitoring and evaluation of progress on the National Plan.

Strategy 5.A: Enhance HHS' Ability to Track Progress

To address policy questions and plan and evaluate new initiatives, the Federal Government needs improved data on people with Alzheimer's disease, their caregivers, and the care and supports that they use.

Strategy 5.B: Monitor Progress on the National Plan

The National Plan is intended to be a roadmap for accomplishing its five goals. It is a document that is designed to be updated regularly. HHS is committed to tracking progress and incorporating findings into an updated National Plan annually.

Appendix: List of Participating Departments and Agencies

ACF	Administration for Children and Families
ADD	Administration on Developmental Disabilities
AoA	Administration on Aging
AHRQ	Agency for Healthcare Research and Quality
ASPA	Assistant Secretary of Public Affairs
ASPE	Assistant Secretary for Planning and Evaluation
CDC	Centers for Disease Control and Prevention
CMMI	Center for Medicare and Medicaid Innovation Center
CMS	Centers for Medicare and Medicaid Services
DoD	U.S. Department of Defense
FDA	Food and Drug Administration
HHS	U.S. Department of Health and Human Services
HRSA	Health Resources and Services Administration
IHS	Indian Health Service
NIA	National Institute on Aging
NIH	National Institutes of Health
NSF	National Science Foundation
OASH	Office of the Assistant Secretary for Health
ONC	Office of the National Coordinator of Health Information Technology
SAMHSA	Substance Abuse and Mental Health Services Administration
VA	Department of Veterans Affairs

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